Vocabulary Taskforce
Draft Transcript
April 14, 2011

Presentation

Judy Sparrow – Office of the National Coordinator – Executive Director
Good afternoon, everybody, and welcome to the Standards Committee's Vocabulary Taskforce, This is a Federal Advisory call, so there will be opportunity at the end of the call for the public to make comment. Just a reminder for taskforce members to please identify yourselves when speaking.

Let me to a quick roll call: Jamie Ferguson?

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
Present.

Judy Sparrow – Office of the National Coordinator – Executive Director
Betsy Humphries could not join us. She's flying back, I think, from Europe. Stuart Nelson?

Stuart Nelson – NLM – Head, Medical Subject Headings Section
Present.

Judy Sparrow – Office of the National Coordinator – Executive Director
Marjorie Rallins?

Marjorie Rallins – AMA – Director, CPT Clinical Informatics
Present.

Judy Sparrow – Office of the National Coordinator – Executive Director
Stan Huff? Chris Chute? I know Chris is trying to dial in. He's calling in from overseas. Marc Overhage? Daniel Vreeman?

Daniel Vreeman – Regenstrief Institute – Research Scientist
Present.

Judy Sparrow – Office of the National Coordinator – Executive Director
John Klimek? Floyd Eisenberg? Karen Trudel? Don Bechtel?

Don Bechtel – Siemens Medical – IT Architect, Standards & Regulatory Mgr.
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Patricia Greim?

Patricia Greim – VA – Health System Specialist: Terminology
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Jim Walker?

Jim Walker – Geisinger Health Systems – Chief Health Information Officer
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Doug Fridsma? Chris Brancato? Bob Dolin? Ram Sriram?

Ram Sriram – NIST – Manufacturing Systems Integration Division
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Lynn Gilbertson?

Lynn Gilbertson – NCPDP – Vice President of Standards Development
Present.

Judy Sparrow – Office of the National Coordinator – Executive Director
Nancy Orvis? Marjorie Greenberg? Did I say Doug Fridsma? Did I leave anyone off? All right. With that, I'll turn it over to Jamie Ferguson.

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
Thank you, all, very much for dialing in today. I really appreciate everyone taking the time. The reason for this call and the main thing that I'm hoping to get out of this call is a discussion of alternatives for our own use on our approach to meeting the new requirements for vocabulary that Doug Fridsma outlined at the latest Health IT Standards Committee meeting, which would be the determination of a recommendation for a single vocabulary or terminology system for problems, one for medications and one for labs. Then our approach to determining useful subsets that could act as a minimum in the context of meaningful use stage two proposed regulations. The main thing that I wanted to discuss on this call is not what those things are, but what's our approach to making those kinds of recommendations and how should we proceed.

There is something else that came up that I didn't anticipate, but that I think would also be a useful discussion for this group today and it came up in the SNOMED meeting this week at IHTSDO. It is really a question on the applicability of short names versus full display names for the chosen vocabulary and a question of whether or not there ought to be, in meaningful use or to support meaningful use, requirements for certification of EHR systems to enable any particular length of display name for the full description of a term. There were a number of different issues around that, such as the potential use of short names for input versus the preferred full display for display purposes. So I do want to bring that up as well just as a discussion item today.

Now, is there anything else that folks want to accomplish on today's call or is that a good agenda right there? Hearing nothing, I'm going to assume that that's good. I hope that folks really jump in on this first item.

I think many of you were aware and some of you were in the recent meeting of the Standards Committee in Washington where Doug laid out basically some tasks for the Standards Committee related to vocabulary that come to us here on the Vocabulary Taskforce to make recommendations back to the full committee. He laid out an agenda for meaningful use stage two—or rather to support meaningful use stage two—where for the certification process we would determine a singular standard for each of those three vocabulary needs. Then importantly, determine recommendations on important subsets that could be a minimum starting set, if you will, for implementers who hope to achieve meaningful use.

Certainly, there are a variety of different approaches that we could take on that. The Clinical Operations Workgroup, of which we're a subset or rather I guess, a sub-committee, did previously actually early on in the stage one recommendations make those single recommendations of SNOMED CT for capturing and documenting problem lists and RxNorm for medications and Laboratory LOINC for labs. One approach would be to essentially un-earth those previous documents, brush them off and see what updates are needed. A completely different approach, sort of the other end of the spectrum, would be to establish actual hearings and get input or there may be other approaches that we can take, so I'd love to get discussion from the group today on preferences, pros and cons of those different possible approaches.

Marjorie Rallins – AMA – Director, CPT Clinical Informatics
How did the Clinical Operations Workgroup come up with the recommendations previously? When you were talking about approach ... have a hearing. Have we sort of been through that process before?

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
There were no public hearings and I'm trying to recall the exact process that was used, but I think a number of acknowledged experts were invited onto the workgroup calls and there were quite a long series of calls that happened sort of right after the establishment of the group. Then there were some materials drafted that went to ONC and then came back and then after that we really started the public hearing process. In other words, we put up a straw position quickly. I guess really we were asked to do so by ONC on a very short timeline initially.

Floyd Eisenberg – Siemens Medical Solutions – Physician Consultant
Yes. Jamie, I think, if I recall, some of that was informed by prior work from HITSP, but I'm not sure if that's all of it.

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
No. I mean, in fact, we were specifically instructed to look at the previously adopted standards, so we looked at CHI (the Consolidated Health Informatics) that recommended, I believe, SNOMED and LOINC and we looked at HITSP that recommended moving towards RxNorm and UCUM and others. So it actually it was a broader set of recommendations, but it did come from standards that had previously been recognized by the secretary and/or adopted by the department.

Chris Brancato – Deloitte – Manager, Health Information Technology
So Jamie is there a notion of how granular we have to be or you're just looking at a metaset?

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
Tell me what you mean by that—in what context?

Chris Brancato – Deloitte – Manager, Health Information Technology
Well, let's say we pick SNOMED and we recommend SNOMED. Is there any notion that there would be—anticipated that we would need to constrain SNOMED to a particular use for meaningful use?

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
Well, that's a great question. In fact, that kind of bleeds over into the second thing that I wanted to talk about, which was using the terms in these vocabularies for input versus for display and for interoperability. So I have to say I don't think that Doug was—

Ram Sriram – NIST – Manufacturing Systems Integration Division
I think that there is something called value sets that are going to define for maybe SNOMED and that's not the entire SNOMED, but only a particular part of it for certain uses and that's—

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
Right, so I think that included in the subsets would be value sets, certainly, in the realm of subsets. But I think that—what I recall Doug talking about in addition to the value sets that would be for purposes of say quality and performance analysis and reporting were minimum subsets that would be used for purposes of actually system certification to say that this is the enumerated list of codes that you have to be capable of capturing data, of using to capture data, to display data, to send data both to patients and to other providers of care.

Chris Brancato – Deloitte – Manager, Health Information Technology
Jamie, I really think there are two issues; one, of course, being whether or not a particular system can support SNOMED or LOINC or RxNorm in the meaningful use scope. A second question is the granularity of these value sets. For example, in a particular quality measure—I know Floyd has—and he can perhaps address this—has obsessed about this appropriately and that's the question of does each

quality measure really have its own value set at the end of the day. My vote would be yes, in which case you get this notion of a proliferation of value sets. Then the whole question of value set management, how users and adopters of meaningful use can or whether indeed they should be required to manage specific value sets for specific use cases. Are we going to get into that kind of issue?

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
Well, that's obviously a great question. I actually tend to agree with you that each measure describes its own value set. That, obviously, may go across multiple different terminologies, coding or classification systems. But I think that what Doug really urged us to focus on is an irreducible minimum for certification purposes that would be really a single enumerated list of codes, for example, or terms that would have to be supported in the certification process, as well as an ability to look up other terms that were needed. He was really talking about it in terms of clinical documentation more than for the quality purposes in terms of what would be in the certification. I think that to the extent that this group feels that we need to go either towards value set management as something that really needs to be tackled in stage two, we can certainly make recommendations in that direction, but that wasn't the impression that I got from Doug's presentation to the Standards Committee.

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
Jamie, I think you're right. I think there are probably a few things that we need to sort of clarify in terms of what we can do in regulations and as we get into meaningful use stage two. As you know from meaningful use stage one is that when we write something into regulation we then can hold people accountable for being certified to that particular standard. However, if we've got things that are rapidly changing or that we need to have some degree of flexibility on, the more prescriptive we are in a dynamic world, the more challenging it's going to be to be able to update that. Because the regulation locks us in to the thing that we have adopted at the time the regulation is published. For example, if what we were to do was to adopt ICD-9 as a vocabulary and within that say these are the subsets, value sets that we need within ICD-9 for the purposes of regulation, if two weeks later we discover that there is a new outbreak of a particular disease that we want to be able to have a standard for, the only way we can have people certify against that is to actually write a new rule and be able to, over the course of 18 months, add those additional value sets or those additional elements into it.

The thing I think that I tried to convey during the meeting that we held just a couple of weeks ago was it is really good if we can identify a particular vocabulary—ICD-9, SNOMED, ICD-10, UCUM, whatever it is—for a particular kind of information or information exchange. Administrative transactions, clinical vocabularies, medications, laboratories, whatever, some of those things and not have multiple options within those particular groups. For the purposes of certification, realizing that there are going to be some folks that have a different vocabulary and that it may be a challenge for them to be able to map everything that they're doing into the kind of exchange vocabulary that we've identified, there may be some value in saying, "Listen, we've adopted SNOMED in all of its wondrous glory. But for the purposes of a clinical summary exchange, we believe this subset of values represents the 95% most common ones. So if you're going to do any mapping from your system and do it in a way that will allow you to pass certification, this is the group that you're going to be held accountable for." It allows us to begin, say, helping the industry by figuring out what would be useful tools that would help people achieve meaningful use because we've constrained the problem to some degree.

The second part of testing is not only testing what is maybe that 95%, but also testing to make sure that people can handle the code that isn't part of that set. What happens if you get a code that isn't part of the one that you were expecting to see—making sure that people can handle that effectively. There are some that we say if somebody sends you a coded term that's on this list, you need to be able to take that as a coded term and do something useful with it; but if it's outside that, you need to not sort of generate an error, but you need to be able to say, "Okay. Here's the human readable version and I may have a manual process or some other way of managing things that aren't part of that subset, but I can do it and I'm not going to have the whole thing grind to a halt." In some sense, identifying what the target is, which is going to be ICD-9 forever for these kinds of transactions, but to get there, here are some ways that we can provide tools and infrastructure and things to make sure that both, people have an easy migration path and it doesn't break if it's not one of that subsets.

Floyd Eisenberg – Siemens Medical Solutions – Physician Consultant
Can I ask a question? Because I'm hearing a lot of discussion—maybe I just tend to think more granularly, but I tend to think a lot of this discussion is very high-level. But if I want to say a specific concept, then I really think we need to be able to specify in what taxonomy, if there is a commonly used standard one or a recommended one we've stayed. If we can't, we should somehow recommend here's the direction we think you should move in or else we're going to have unstructured data that we're not going to be able to move to in the future. So I think we have to do it by concept, not just a couple general ones. When I say concept I mean med—of course, we've discussed that before and that's in the rule—allergy, procedures, you name it, but it's everything. It's not just the routine med and laboratory.

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
Well, you really mean by data category, not necessarily by concept. You don't mean Amoxicillin 500mg tablet that we specific, but—

Floyd Eisenberg – Siemens Medical Solutions – Physician Consultant
That's a semantic issue, but yes. I mean by category. Right. Yes.

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
So the question that I had posed to the group, Doug—and I'm not sure at what point you joined—is what approach do we want to take as an advisory workgroup or taskforce to try to answer your question. I wonder—do you have a sense of the degree of public input versus expert deliberations here in the workgroup and so forth that might be very useful?

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
I don't have a sort of pre-supposed approach. I do think that there are some things that are pretty well accepted and for which we've already begun to sort of lay the track towards in meaningful use stage one. In those circumstances it may simply be an open discussion that this committee has that has public input that will allow there to be sort of an agreement that comes up and then recommendations that go to the HIT Standards Committee. You may find that there are other things that are more controversial or for which it is important to sort of understand how those might fit. You might want to have some additional hearings or some additional input in that regard.

It could be that you kind of come up with a straw man set and then hold a hearing that basically says, "This is kind of what we think needs to happen." You could break up that hearing into things like its impact on the vendors, the challenge or the good things about that with regard to providers and workflow, what is currently being used and supported. There are a variety of different ways that you could do it. I think at the end we have always been signaling that as we move through the stages of meaningful use we want to get to the point where we begin to reduce the optionality and converge on common ways of doing things. But to do so in a way that, again, makes it easy for people to get on that escalator, be able to kind of know how to migrate in that direction and making sure that we've got a practical strategy because when you pick a winner that means by default you've also picked a loser. Those folks we need to make sure have the support that they need to be able to kind of move forward.

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
Right. Exactly to that point, one of the things that has been discussed I think in some of the HIT Standards Committee discussions was whether there's the possibility of specifying something now that may not be effective until perhaps stage three or some later compliance date as a mechanism for giving that kind of a glide path. Is that realistically something that we can end up recommending or is that really off the table for us?

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
I don't know. I'm not sure—I'd be curious what others think about that before I answer.

Nancy Orvis – U.S. Department of Defense (Health Affairs) – Chief

Jamie, I have a good opinion on this one. Of course, I always have an opinion, Doug, but I think for us one of the things that's been missing is the annual update to recommended standards and specifications that came out with HITSP. In that respect what Jamie's asking for, say—we weren't going to use it in meaningful use, but if the HHS secretary were also able to say, "Here's the 300 laboratory ordering test-… code set," that we would have something out there then that we could start to target and use as reference implementation for lab orders, for example. I think where that came out as with the S&I framework, what we're missing right now is having an annual mechanism that allows the nation to move forward on new target standards and terminology sets and as well as add to the mail on meaningful use. I think it's important to have both, because as I told Betsy Humphreys from the Library of Medicine, she said, "Why aren't you, DoD , using that?" I said, "Well, normally we've been putting things in our target standards list that have been blessed by the secretary and if that changes, we need to know about it."

Chris Brancato – Deloitte – Manager, Health Information Technology
Yes. Really, Nancy, you're getting at the whole notion of U.S. realm, which I strongly agree with.

Nancy Orvis – U.S. Department of Defense (Health Affairs) – Chief
I ... one ….

Chris Brancato – Deloitte – Manager, Health Information Technology
But I think, to answer your question, Doug, I think we should make recommendations about glide path kinds of issues and one of them has already been brought up in this call that I think Jamie asked explicitly, which is the value set problem. If we don't get to value sets, then frankly, a lot of the practical implementation of interoperability is going to be severely compromised. I wonder if a phase three target would be the ability to somehow manage or use value sets and that would imply, oh by the way, everything Nancy just said, which is annual updates or at least specification of what, in fact, those value sets are. We don't have to go to my vision of 47,000 value sets necessarily for version three, but on the order of a dozen would actually be great progress.

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
Well, and all I want for Christmas is a U.S. realm. So I certainly agree that I think those are parts of what we need to do in terms of being able to manage effectively vocabularies that are specific to the United States and being able to keep track of and update and the like.

I think to the point about the specifics of a value set, the tension that we have is that in a regulatory process to have a specific value set identified and put into regulation will lock you into that value set for the purposes of certification. Now, that may not be bad. That may be a reasonable thing to do, but the regulatory process is incredibly slow and not responsive to the rapidity at which many times vocabularies and value sets need to change and update in response to both changing situations in the world. As well as just because we've tried things and we realize we need to update it or to modify things. It would be tremendously challenging—not impossible, but challenging—to try to put through a regulation on value sets every year.

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
Doug, that sounds to me like a very convincing argument for potentially making recommendations on what the reference terminologies are and a minimum subset that would be part of certification for certified EHR systems to be able to handle in each of those reference terminologies. Then we may consider without specifying in regulation sort of the enumerated lists of codes in the different value sets, but rather have some functional capabilities about being able to manage value sets that may be more of the nature of a system function that could operate for whatever value sets are determined by a different process.

Chris Brancato – Deloitte – Manager, Health Information Technology
Well, that sounds rational and it might just be quite practical, but before we necessarily take that approach, Doug, can you help me understand what the process is for the twice-annual updates that are mandated for ICD-X—ICD-9 presently, ICD-10 soon? Because, as you know, that's actually written into regulation by HIPAA; it's part of the requirement to use the HIPAA terminology. We also know that there is a twice-annual federal update cycle on that, which providers are obligated to use.

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
Yes. We actually, in the first stage of meaningful use, had a lot of discussions about whether we could use a similar mechanism. So we talked to the Office of General Counsel and others to try to figure out exactly how to do some of that work. I'm probably not the best person to think through all of the nuance of that and I would defer to both, Steve Posnack and to Jodi Daniel about that, but my understanding was that there was a change of heart in our ability to have that degree of flexibility. We wanted to be able to adopt kind of a minimum standard that would go into regulation and the ability to update that through other mechanisms. When I say it's challenging, but not impossible, clearly there are organizations that do have that ability to do that.

The challenge we have, of course, is that it also has to flow through certification. It has to flow and get updated in lots of different ways. You begin to run out of months to be able to do that. That's the only challenge. It's not that it's not possible and that there aren't other models. We got some push back in terms of being very flexible around vocabularies and value sets. If the recommendation from this group is that we need to revisit that because it's truly the only way to do things, then we can go back to OGC and see, but there were some challenges going into meaningful use stage one with just our ability to, from a regulatory perspective, have some flexibility. If you create the certification criteria and it's supposed to be good for two years and then you update it mid-cycle how does that all work? There was a bunch of different questions that came up and I defer to Steve and to Jodi to the nuance of why that was a challenge for us.

Chris Brancato – Deloitte – Manager, Health Information Technology
Well, I'll go out on a limb and, at least as a single member of this sub-working group, register my belief that unless we have comparable and consistent vocabularies we don't have interoperability—period.

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
I might nuance that a little bit, but others can comment.

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
Well, I mean I don't think that we're going to, frankly, get to interoperability in one step and so it seems to me—Doug, please correct me if I got it wrong, but—I think what you're asking for is what's the right step for now on that path.

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
Yes. Yes and I think when I think about the glide path and how we might take those first steps towards this vision that Chris has around sort of true and complete semantic interoperability, I think too of some of the comments that Wes has made during the HIT Standards Committee. This notion of being able to have some gracefulness around the edges with things, so I think it's possible to say, "Listen, we want true, semantic interoperability around some of these core things. But we don't want things to break if there's a new code or there's a new code set or there's something new that we want to add because there's an influenza pandemic that we need to get data collected in a standardized or coded way. We didn't anticipate it and we don't have the time to be able to go through the regulatory process to require it." Just having the ability to say we want people to, in some area, begin the process of getting semantic interoperability, around that to make sure that it's not part of that value set or that subset of the vocabularies that the systems aren't going to break. Then gradually we can expand the scope of what gets covered. We may never get to 100% because there are always going to be potentially new things that come on board or old terms that will get deprecated or other things like that, but that we will kind of move towards a more semantically interoperable future.

Chris Brancato – Deloitte – Manager, Health Information Technology
Yes and I can accept that there's a rational path. I would want to point out that what you articulated and what I was saying are not in any way in conflict. Exception management is quite distinct from having at least the specification of standard value sets.

Marjorie Greenberg – NCHS – Chief, C&PHDS

I hear you, Chris. I just wanted you to know that I'm on the line. I'm sorry, I was a little late.

Marjorie Rallins – AMA – Director, CPT Clinical Informatics
I support Chris' comments and I want to comment on Doug's notion about gracefulness around the edges. My comments are based on the retooling work that the PCPI Group did—and Floyd, you might want to jump in. The notion of value sets is more than sort of adding a new code for a pandemic virus or what have you. Value sets, in the context that we think of them now, don't necessarily capture the full capability of SNOMED. A straight list of SNOMED codes in a value set and locking that down just doesn't work. There are always notions for or needs for post-coordination and the list is never complete. I think if we're going to have the discussion we really need to think of the standards that we recommend how each one of those would behave within a value set, because sort of a straight list, treating them all the same just doesn't work. It's like when you have children. It just doesn't always work.

Stuart Nelson – NLM – Head, Medical Subject Headings Section
I wanted to say that clearly to me the real issue here is the ability to continue to evolve, let the terminologies evolve as they need to and yet be incorporated. I would be in favor of saying in the rules, the regulations that—and we could recommend a set of standards for how a value set is arrived at and timing of that. Go ahead and then say the regulations for using those value sets need to just say you must have a process where you keep current with the ... version of the value sets and not worry about I'm going to have to mandate this list of enumerated codes. I think mandating a list of enumerated codes is a way to guarantee failure.

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
Stuart, I agree with you in the context of the value sets that we're talking about, for example, for quality and performance measures. But I think that actually an enumerated list of codes that may be adjusted from time to time—such as the 300 most frequently ordered clinical lab tests or the 2,000 most frequently used problems in a problem list. Things like that, for purposes of certification, can guarantee a minimum set of functionality in the EHRs that are being adopted that I think is quite useful.

Stuart Nelson – NLM – Head, Medical Subject Headings Section
I think you're right. It could be very useful in being able to help evaluate those things, but I put those things out and just say this is it. Put that in the form of a regulation; I can't see that.

Marjorie Rallins – AMA – Director, CPT Clinical Informatics
I agree with that. Practically speaking and given our past experience, I just think it's a great concept. I just don't think it works for certain standards.

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
Doug, can I get perhaps a reaction from you to this part of the discussion? Perhaps you could help enlighten us if there's some different mechanism that ONC might have in mind by which the minimum set of codes in these vocabularies that would be used for certification, how that would be updated?

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
Do you mean the process, the process by which—?

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
Yes. I mean is there a way to not bake that—? So if you're talking about a minimum list of terms or concepts that has to be used in certification is there a way to reference that so that it can be updated without literally putting the enumerated list of codes in the reg itself?

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
Well, I think we're exploring a lot of different approaches. I don't know if there is any one right approach. We would clearly need to get feedback from some of the regulation experts about this, but there is the possibility to adopt a vocabulary, kind of a reference vocabulary in its entirety as the standard. Then provide mapping tools and other things with the expectation that for the purposes of certification, since we

can't test that you have every single code covered, we can test that you have the codes that are part of a testing suite, plus checking for not breaking if you send a code outside of that testing suite.

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
Right. So that could result in testing against a very, very small list of codes just to ensure that there's a fundamental capability, right?

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
Yes, and that could be three terms. It could be 300. It could be 3,000. We'd have to work to try to make sure that we've got with NIST and others that we have a testing infrastructure that would help us implement the policy and standards that we'd like to see to get us the interoperability.

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
But essentially that then delegates to the writers of the test script the determination of what the minimum set is?

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
What would likely happen is that from a regulatory perspective there would be certain things that would be written into the regulation, but there may be other processes through the, perhaps, Federal Advisory Committees or the like that could do that. There are other ways as well. We've got something that we're required to do around NwHIN governance. When you think about the specifications for the NwHIN, it's the standards, services and policies. That's sort of how we've defined it. So creating a regulatory process or creating a governance process as part of the NwHIN, if those specifications were inclusive of vocabularies and value sets that would be another mechanism that you might be able to do to manage that. So you could run it through the FACAs. You could run it through the standards and interoperability framework, which is something that is the carry on or sort of the next generation of much of the work that HITSP has done.

There is a variety of different ways that you could do that. I'm not advocating for any one of those approaches and I don't have any sort of hidden agenda that one of them is going forward and the other ones are not, but there are some different ways that you could do that. You would have to, of course, in the regulations indicate where those updated vocabularies would be and you'd have to make sure that there was a process either defined in the regulation as part of NwHIN or through the Federal Advisory Committee that gives us an approach. That would have to be defined in that way, but this group, this team, can probably work through some of those mechanisms and think about the pros and cons of one approach versus another.

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
So, for the taskforce members, what I'm thinking is that we may want to have, we may want to establish a few other phone calls so that we have a chance to sort of go away and collect our thoughts on some of these alternatives unless anybody else has sort of fully formed opinions on this that we can debate. I certainly don't. I mean I think there is a lot of food for thought here from my own perspective. I'm not trying to cut off the discussion now; I'm just saying that we're going to need more calls before we come to agreement on even a general direction. That's my sense of it. How do other folks feel?

M
You're right, Jamie. We're going to have a lot of talking through to do.

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
Yes. Okay. I wonder if perhaps I could just a placeholder on this conversation and bring up the other topic that I mentioned at the top of the call for the agenda and then come back to this, perhaps from a slightly different angle. What I wanted to talk about is something that was part of a number of different discussions at the IHTSDO meeting this week and that is on the intended use of short names versus full display of the reference terminology.

One of the things that has arisen is a situation where a number of the most popular EMR software systems don't give their implementers the ability to display the full, preferred description of terms—certainly in SNOMED, as well as ICD-10. They have length limitations of 60 characters or 54 characters—those were some numbers that we heard from different participants—and yet there are certainly some cases where the length of the description is quite a bit longer. For the most commonly used SNOMED problems in the problem list that were identified by NLM, I'm going to say roughly 10%—it's a little bit under 10%—of those preferred descriptions would exceed those length limitations.

One thing I wanted to put on the table as a possibility for this workgroup to undertake would be a survey of the EMR vendors. That we could just send out a letter from the workgroup asking for information so we can understand of the certified vendor systems that are out there, how many of them have these kinds of length limitations for the kinds of vocabularies that we're going to be recommending. Now, there certainly are a number of folks in the field, who have very strongly held beliefs about abbreviations being a patient safety issue. Yet, at the same time, I think there are also sort of equally strongly held beliefs about abbreviations and acronyms being extremely useful for input. So there may be, in fact, a difference between using short names and acronyms and abbreviations for input versus what might end up being used for display to a clinician or to a patient in terms of the patient's access to the same information.

One of the ideas that I wanted to throw out for discussion was based on the kind of input that we might get if we really understood what's available in the different systems. That we may want to consider a possibility of making a recommendation to the Standards Committee to include functionality in the upcoming certification process relative to the vocabularies that we recommend that there be capabilities in the certified systems to actually display the full description of the term for display purposes. So I just wanted to open up a general discussion here on that topic and see if that's something that is of interest to the taskforce.

M
It's a very important issue, Jamie, and I'm aware of systems that actually have 40-character limits. It may be unrealistic to require systems to display the full name of all codes because, as you know, there are some coding systems with literally hundreds of characters in their fully specified string that I don't know of any systems that could actually accommodate that. So part of the question would be what is a reasonable specification that is somewhere between hundreds and perhaps more than 40 that allows a non-ambiguous representation of critical concepts. Another alternative is to say, okay, let's restrict it to the most common terminology elements, because those terms with hundreds of characters are mostly the odd ducks of course and are rarely seen, but it's not a trivial issue exactly how to specify that.

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
Right. Now, I do have at my fingertips some statistics that were done recently by … over at NLM looking at SNOMED descriptions in particular. So the analysis looks at the core problem list, the CMT top 2,500-problem list, the combination of those. It looks at the cardiology problem list of 1,000 concepts and then looks at basically all descendants of clinical findings and observable entities in SNOMED—over 100,000 concepts. So I think of all of the different subsets of the frequently used problems, there is a maximum between 135 and 177-character length. The average length is … of interest, is about 25 or 26, but still, there is a significant proportion that are over 50 characters. For example, for cardiology, fully a quarter of the descriptions are over 50 characters. This is just to kind of throw out some information for the discussion here.

Lynn Gilbertson – NCPDP – Vice President of Standards Development
Jamie, just two thoughts we've been wrestling with in our task groups: One is in discussing RxNorm and how the names—the descriptions may not be the most appropriate for display purposes. Not that there's anything wrong with the name, it's just it's maybe not the most appropriate for that perspective and what should the industry recommend for that. The other side in discussing when working with the National Cancer Institute, we actually built with them more of a preferred display list actually into the subset so that it had the right information, but was not the fully elongated name that was great for the vocabulary rigor, but was more of what might be popped up on a screen. So we're working on both different situations and treated them differently based on the input of the industry as to what they were going to use that for.

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
Right. I think the context of use is exactly the point that I think this gets to. It's something that—I forget who it was—somebody brought up earlier on the call—it might have been Floyd—to say that it really matters what the intended use is of these subsets as to what they are and how they might be specified in regulation. For example, things for input versus for display, as I think you're saying, may be very different.

Jim Walker – Geisinger Health Systems – Chief Health Information Officer
Jamie, rather than start from average lengths or convenience, I'd like to approach this from the standpoint of cognitive psychology. There is theoretical and not nearly enough empirical reason to think that the shortest, unambiguous and comprehensive name for something is the best in that people can read it faster, are less likely to quit reading it before they get to the business end of it and so forth. It's my experience doing a fair amount of trying to name things for display that very few vocabularies of any sort appear to have been designed with very much thought given to how rapid and error free the comprehension of the labels they create would be. I think it would be a serious mistake to put into regulation a requirement based on practically no empirical evidence.

Just to wind up, I'd say we need research to document what is the best way to name these things so that there are the fewest errors, but I think right now, as you said earlier, we have strongly held beliefs, but practically no evidence. That's not a good place to start writing regulations from. Just as an anecdote, we often, although not always, are working in a system where 43 characters is the limit. It is a very rare test or medicine or anything else that we need to name, a finding, whatever it is that isn't improved by an effort to get it close to 43.

Stuart Nelson – NLM – Head, Medical Subject Headings Section
I want to comment; there are a couple of different issues that are floating around. One is the … into which something is an unambiguous name. Because what's unambiguous in one context, for example, to a cardiologist, might be quite ambiguous when it got outside of this narrow domain of cardiology. The problem—I'm going to speak as a terminologist for a minute—that the terminologists have is trying to make sure that their names are sufficiently unambiguous to be used. That's for something that's a reference terminology.

Interface terminology can be quite different. That's for one reason and that's why I started putting all of these synonyms into RxNorm, because they're shorter and still unambiguous, but not so long and convoluted a name as the formal normalized name. But you can carry it too far. For example, some of my favorite vocabularies almost require that whoever is doing data entry be a board certified magician in order to be able to interpret what was meant by this "unambiguous" name. So I think a terminology can get carried too far along into the point of being unambiguous; whereas you have to recognize that there is some kind of happy medium. I certainly do think that we need to know what that happy medium is. I'm not sure that it would suit anybody's purposes that we specify what an interface terminology be.

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
So let me just play devil's advocate for a minute: Would it be okay with everybody here if a certified system could handle SNOMED and LOINC and RxNorm, but could only display to the clinicians, who were using the system, two dozen characters or less?

M
I think we could say no to that.

Jim Walker – Geisinger Health Systems – Chief Health Information Officer
Jamie, I'd say 50 wouldn't be too far. I would bet that more than 99% of names could be well presented in 50 characters.

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy

Yes. Well, in terms of the preferred descriptions for SNOMED, basically all of the different subsets that we've looked at for problem list came in at about—50 characters would handle 95% of those except in cardiology.

M
Yes, but you had said two dozen, which, to me, is 24, was that—?

M
Yes.

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
That's right. No. No. No. That's right. I was playing devil's advocate. I was testing how short is too short, but now I'm looking back at sort of the actual SNOMED statistics of the description lengths and for all three of the most popular problem list subsets identified by NLM the 50-character length limit would capture 95% of them. The one that's the outlier—the fourth one that's the outlier is the one for cardiology where a 50-character length limit would capture only 75% of those preferred descriptions.

M
I strongly agree with Jim Walker's observations and conclusion. The difficulty is unless we're going to have vendors or, worse, providers, which is presently the case, shorten these longer strings to fit the user interfaces it doesn't matter what we say because presumably, important concepts won't fit. I mean, the ideal would be to say is there a way, either in the U.S. realm, the mythical and once in future U.S. realm that we could make a national subset that would, in fact, fit so that not every provider had to shorten these terms, which, as I've said, is now the case.

Jim Walker – Geisinger Health Systems – Chief Health Information Officer
Right. If we were going to right, a regulation we ought to write a regulation that terminologists have to stick to 50 characters.

M
Well, somebody has to stick to 50 characters.

Jim Walker – Geisinger Health Systems – Chief Health Information Officer
In which case there would be mass resignation on the part of the terminologists.

M
Yes. Whether SNOMED will deliver that is another matter or whether there has to be a U.S. value set for whatever we want to call it, version that does fit through a one-time, let's just let one group do it once, shortening of these extra-long strings so that ambiguity is avoided. Personally, I think that would be a delightful solution, but I don't know that there's any infrastructure available to us to propose that kind of a project.

Jim Walker – Geisinger Health Systems – Chief Health Information Officer
I agree and I would propose that we recommend that NLM or somebody fund a team that really has human factors and cognitive psychology expertise, as well as terminology expertise. Because my thesis, my hypothesis would be that you could improve them at the same time that you shorten them. I mean empirically that people made fewer errors reading them and interpreting them.

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
Well, I did want to bring up this topic for discussion because it did seem to me that if we're talking about the potential for mandating a minimum subset of these vocabularies that we ought to be cognizant about the actual capabilities that clinicians will experience in implementing these systems in terms of displaying and using these reference terminologies.

Jim Walker – Geisinger Health Systems – Chief Health Information Officer

Just very quickly, in a practical way we could also—right now, for our information exchange, we're trying to create usable versions of LOINC that would be readable across a region. We're working with LOINC and trying to find funding to get some testing by different kinds of users. There would be practical ways that at least as we're doing this we don't make it one-offs, but try to do it together.

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
So I mean I don't think it's out of the realm of possibility for this taskforce to make recommendations to the Standards Committee that to support the meaningful use, if you will, of these reference terminologies that this kind of research is needed in order to inform the potential for future regulations on this.

Jim Walker – Geisinger Health Systems – Chief Health Information Officer
Agreed.

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
But then that still, I think, leads us back to an earlier discussion point that was part of our other part of this call, which is what is the intended use of these terminologies. What is the exact use of them in the certified systems? Is it intended for input? Is it for display? Is it for interoperability? Is it for all of those? Is that something that we need to—well, how explicit do we need to be about that? What are some of the parameters around that?

Jim Walker – Geisinger Health Systems – Chief Health Information Officer
It's clear when you try to work with them that—at least the ones I've tried to work with—do not have a concept of sort of a base name that contains everything that's needed to characterize it and then, potentially at least, different names that would be used for different audiences. I would have to see research to be persuaded that input and output names should be different, but the idea is is this a name that should be understandable by anyone using a health information exchange and we'll just say by a well-trained nurse or a PCP or is this something that—

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
Well, let me just test that. So you might say a CBC or a CBC with Diff would be an abbreviation you would use for ordering, but if you were then going to send the result to the patient for their use of their own information, would you just say that—CBC with Diff—or would you say Complete Blood Count with Manual Differential?

Jim Walker – Geisinger Health Systems – Chief Health Information Officer
The only study I've ever seen published—and there must have been more—found that patients felt disrespected by the use of patient friendly language—that is heart attack instead of myocardial infarction. So there again, I think we would be in danger of making a bunch of guesses that might be wrong.

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
I'd actually have to say our own experience in that and interviewing our patients, actually in the thousands, is that they want to use the same lingo as their care team, but that in fact, some of the abbreviations are confusing, so they do like to see the medical term spelled out.

Jim Walker – Geisinger Health Systems – Chief Health Information Officer
That's fine. We just need research.

M
I think one of the things that is going to be important as we think about scope and what we need to do as we go through stage two and stage three of meaningful use is there are a lot of different moving parts. There are things that are important for exchange and if we're using a standard for exchange is it permissible that within an institution they could provide their own shortened versions of that that are specific to the way in which their providers communicate. As long as when they exchange they use the standardized codes that then would allow someone on the other end to use the same concept, but to say CBC with Diff versus CBC with Differential, for example.

I think there is an emphasis with interoperability on making sure that there's consistency between organizations and allowing within an organization things to be a little bit different. Now, that having been said, there are also concerns around usability and certainly, that is an area of interest as well. In that sense there may be some things that would be preferred with regard to usability, but I think it's important to make those distinctions so that we're using the right tools and the right kind of perspective as we think about the terminology.

Jim Walker – Geisinger Health Systems – Chief Health Information Officer
Yes. I mean I'm responsible for an internal community of language use and for an exchange that tries to represent, recognize external. I would kill for terminology that had a machine name or machine number or a core thing that would be transmitted from one organization to the other for exchange, but also came with a display layer that had been tested for recognizability and clarity and non-ambiguity that I could use instead of having to recreate those. I think most people who have to do this would.

M
I'm saying that there's value, I think, in both, but the first around identifying sort of both subsets for exchange perhaps is a different problem than identifying a code subset that includes those names that could be potentially used by lots of people to make their job a lot easier. You need the first for consistent, semantic interoperability between organizations. You may or may not need the second to have that.

Jim Walker – Geisinger Health Systems – Chief Health Information Officer
Yes. Fair. Although from a—yes, maybe that's the question of whether you come at this as a technologist or a cognitive psychologist or something. From the actual use-it-on-the-street level, having names that you could be confident were optimized, there might be a lot of people who would rate that higher than the other or at least say that the semantic interoperability problem is a lot closer to being solved than the usable label problem is.

M
I would endorse that. We actually, as an organization—and I'm sure, quite frankly, every organization that uses terminologies—spend considerable resources in shortening them to make them usable in our systems. I mean if you think of it as a national tax, in a sense, on the healthcare system it's non-trivial—

Jim Walker – Geisinger Health Systems – Chief Health Information Officer
Yes.

M
—…the entire system. Further, Jim's points about having content that is validated and verified in some sort of professional context, I think, is a patient safety issue at some level—

Jim Walker – Geisinger Health Systems – Chief Health Information Officer
It is.

M
—that would be in the public's interest.

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
Okay. So I really appreciate that discussion. I think that's going to give us more to come back to, frankly, in terms of some of our future deliberations.

Getting back to sort of the core question, I think, for this call, in terms of what's our approach to determining the vocabulary recommendations and the subset recommendations, it seems to me we've had actually quite a lot of discussion here today. Do folks have any very strongly held feelings or is this a question that we want to try to just schedule another call to come back to and organize some discussion around alternatives? How do others want to proceed here?

Ram Sriram – NIST – Manufacturing Systems Integration Division

Do you want us to ... or something like that where this particular group can put in their comments and things like that so you can track them down?

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
Yes, that's certainly an idea. We have not done that yet. Judy, is that something that we can set up?

Judy Sparrow – Office of the National Coordinator – Executive Director
I can certainly talk to Altarum about it and see what we can come up with. We do have one more call scheduled for May 5th ….

Jim Walker – Geisinger Health Systems – Chief Health Information Officer
Could I ask Doug a question? Is Doug still on?

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
I'm still here.

Jim Walker – Geisinger Health Systems – Chief Health Information Officer
Would it be feasible to say we're going to tap RxNorm or whatever as the terminology you have to use for drug names and we're going to have NLM or somebody create use case specific vocabulary value sets? They will be non-binding and they will be updated as appropriate. You can use them or not use them. They'll help you guide your use of RxNorm or not as you choose. Would that be a feasible way to approach this?

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
Well, certainly, we've been having conversations with the National Library of Medicine to try to help us with some of the tools and the infrastructure that we anticipate may be needed. I think when we adopt something in regulation the expectation is that that's what we can hold people accountable for. We know that it's simply not practical to be able to test that an EHR can manage every single SNOMED term within their EHR. It may make sense to say that, as you sort of suggest, let's create some non-binding subsets that may make your job easier and then we can explore some of these mechanisms for how these value sets might be governed or might be updated or things like that, but I'd like us to take some concrete and incremental steps. I think it's sort of a non-starter to say ICD-9 or ICD-10 or SNOMED or—insert favorite vocabulary here. I think we really need to start focusing on identifying those high-level reference vocabularies that can give the industry guidance and then give them some short-term, incremental wins. That doesn't leave everybody behind as we move towards this more global and more sophisticated interoperability.

M
If I could comment as the father of RxNorm, you've just got to tell me how I'm going to decide which is the appropriate name. When we create synonyms that we think are probably more appropriate than our fully specified names it can vary a great deal depending upon what somebody really wants. Without some kind of background on how to make a selection it's kind of like it's anybody's guess what's the appropriate name.

Jim Walker – Geisinger Health Systems – Chief Health Information Officer
Yes. That's why I really mean we need research, because I mean I spend a fair amount of my vacation time guessing what the most appropriate name for different audiences is and my major experience is feeling completely like a fool trying to do it, but you've got to try. It would be much better if we would get some research funded so we actually could say for this audience this setting is reasonable—or these three all function the same and so use the one that matches your local area's usage.

M
Yes. Well, that's what we try to do in RxNorm is these are things that would be appropriate, might be a reasonable entry point, but we have no real way of knowing which would be the best entry point.

M

Yes. Agreed.

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
I also think that it's important to understand the problem that you're trying to solve. If what we're really trying to do as we move towards meaningful use stage two and three is moving towards interoperability, as well as making sure that we've got usable and good usability around the terminologies. Making it clear that if we've got this big problem that we're trying to tackle, what's the bite that we want to take in this next round that will kind of get us some successes. Then lay the groundwork for the next bites and the next one after that so that we can start to tackle this bigger problem.

Jim Walker – Geisinger Health Systems – Chief Health Information Officer
Yes. I agree, Doug. By the way, my main plea was just that we not put something into regulation that we don't have any knowledge that it's the right thing to do.

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
Amen to that.

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
What I'm going to suggest is that we try to wrap up this call and schedule and work with Judy to schedule a couple of additional calls. Does anybody want to take a different path other than that?

M
Sounds good.

Judy Sparrow – Office of the National Coordinator – Executive Director
Yes and we do have that one call on May 5th—

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
Right. Let's look for dates—I mean my own thinking is that this is both, a relatively urgent and important topic that if we could find an hour every two or three weeks to come back together that would be great from my standpoint.

Judy Sparrow – Office of the National Coordinator – Executive Director
Okay. Great. Let me work with you all on another meeting or two.

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
Does anybody disagree with that target?

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
I mean I think that that would be a reasonable strategy. One of the things that we may want to do within this group as well is get some periodic check-ins on some of the S&I framework initiatives that are ongoing. So, for examples, as we think about the laboratory interfaces project I think part of that would include the identification of LOINC subsets, for example. We may want to, at some point, get ... or someone else to come in and give us an update as to where they are with those sorts of things. The same may be true of some of the transitions of care activities, because they may be looking at some value sets or some subsets to help with that. So I think there are also some other pieces that we may want to pull in just so that we can be responsive as we move towards the fall and the need to sort of move into regulation mode—that we've been tracking some of the other activities that may touch on this workgroup.

Patricia Greim – VA – Health System Specialist: Terminology
I just want to tag onto that thought. The kinds of conversations that we're having right now about terminologies, would those conversations be well served in an arena such as would be available with the support of the standards and interoperability framework?

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability

I think it's always helpful when we ground discussions in real projects that are trying to implement those solutions. So there may be some value there. In fact, they can give us updates and if there are things that they're struggling with, perhaps this group can address some of those issues. I know that in the Direct Project, in that initiative, there was a lot of good synergies between some of the Privacy and Security Teams within the Federal Advisory Committee and the work that they were doing as well. So we may think about how best to leverage those activities as well.

Patricia Greim – VA – Health System Specialist: Terminology
I know we heard a lot of testimony earlier that linked the idea of any time there is a national requirement for reporting that it be linked to like a national standard for content. So that's why I was thinking that the standards and interoperability framework might be with the use case, such as has been discussed here might be a good place to gather consensus for development of value sets.

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
Okay.

Judy Sparrow – Office of the National Coordinator – Executive Director
Should we look for public comment?

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
Yes, please.

Judy Sparrow – Office of the National Coordinator – Executive Director
Operator, can you see if the public wishes to make a comment?

Operator
We do not have any comment at this time.

Judy Sparrow – Office of the National Coordinator – Executive Director
Thank you, everybody. Thank you, Jamie.

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
Thank you very much. Judy, let's see when we can schedule a couple of more calls.

Judy Sparrow – Office of the National Coordinator – Executive Director
I will do so. Thank you.

Jamie Ferguson – Kaiser Permanente – Executive Director HIT Strategy & Policy
Thank you very much, everybody. I appreciate it.